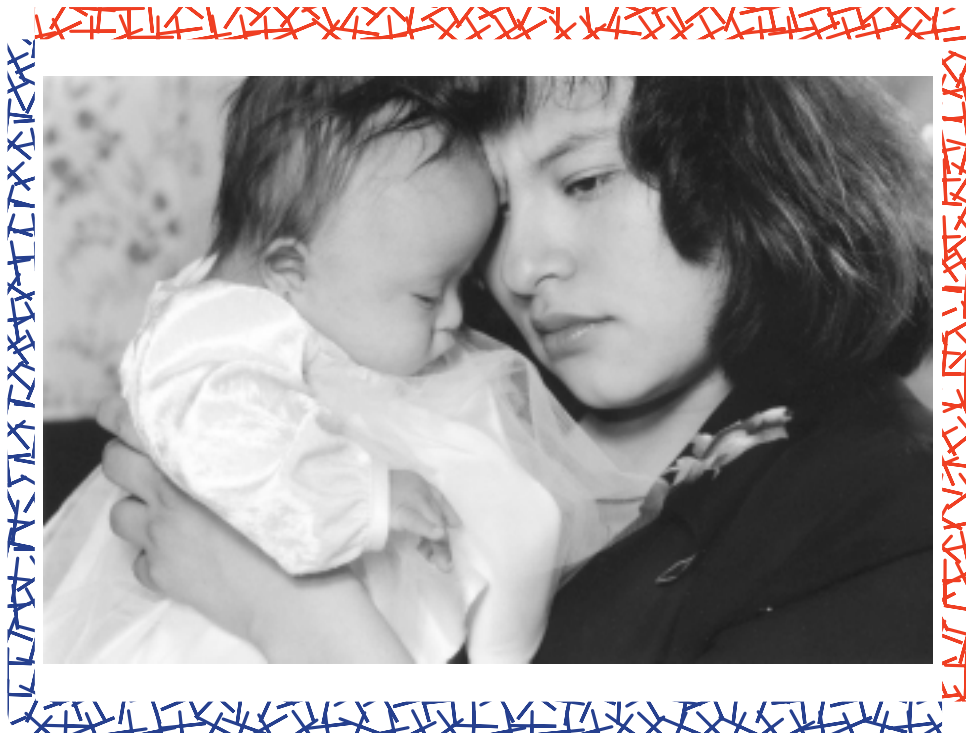


# TEXAS BIRTH DEFECTS MONITORING DIVISION



## Texas Birth Defects Registry Report of Birth Defects Among 1996 and 1997 Deliveries



William Reynolds Archer III, M.D.  
Commissioner  
Texas Department of Health

J.C. Chambers  
Chair  
Texas Board of Health

Texas Birth Defects Registry

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# **Report of Birth Defects Among 1996 and 1997 Deliveries**

Editors:

Mary Ethen, M.P.H., Epidemiologist  
Amy Case, M.A., Information Specialist

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# Executive Summary

**Overall Prevalence:** A total of 9,636 cases was detected with one or more of the birth defects monitored in 1996 and 1997. Of these, 9,300 were live born, corresponding to 3.1 percent of all live births in the registry coverage area. The three most common birth defects were heart defects: patent ductus arteriosus; atrial septal defect; and ventricular septal defect. Rounding out the ten leading birth defects were hypospadias or epispadias; obstructive genitourinary defect; pyloric stenosis; Down syndrome; cleft lip with or without cleft palate; hydrocephaly; and cleft palate alone (without cleft lip).

**Age Patterns:** There were 14 birth defects with statistically significant variation among mothers of different age groups. Younger mothers had the highest rates for reduction defects of the upper limbs; reduction defects of the lower limbs; and gastroschisis. Both younger mothers and older mothers had higher rates for microcephaly and stenosis or atresia of the large intestine, rectum, or anal canal. The highest rates were found among older mothers for the following birth defects: hydrocephaly; tetralogy of Fallot; ventricular septal defect; atrial septal defect; endocardial cushion defect; pulmonary valve atresia or stenosis; patent ductus arteriosus; Down syndrome; and Edwards syndrome.

**Racial/Ethnic Patterns:** Fifteen birth defects showed statistically significant differences among mothers of different racial/ethnic groups. The rates of cleft palate alone (without cleft lip) and pyloric stenosis were highest among births to non-Hispanic white mothers. The rate of microcephaly was highest among births to African American mothers, while rates of hypoplastic left heart syndrome and craniosynostosis were significantly lower among African American mothers, compared to mothers of other racial/ethnic groups. Rates were highest among births to Hispanic mothers for the following conditions: spina bifida without anencephaly; hydrocephaly; anotia or microtia; ventricular septal defect; atrial septal defect; patent ductus arteriosus; cleft lip with or without cleft palate; stenosis or atresia of the large intestine, rectum, or anal canal; and reduction defects of the upper limbs. The rate of hypospadias was significantly lower among births to Hispanic mothers, compared to mothers of other racial/ethnic groups.

**Sex Patterns:** Fourteen birth defects showed statistically significant differences between males and females. Birth defects that were more common among females than among males were microcephaly; ventricular septal defect; cleft palate alone (without cleft lip); and congenital hip dislocation. Conditions that occurred more frequently among males than among females were transposition of the great vessels; aortic valve stenosis; cleft lip with or without cleft palate; pyloric stenosis; Hirschsprung disease; hypospadias or epispadias; renal agenesis or dysgenesis; obstructive genitourinary defect; reduction defects of the lower limbs; and craniosynostosis.

**Regional Patterns:** Nine birth defects showed statistically significant differences among regions. Region 11 had the highest rates for ventricular septal defect; atrial septal defect; pulmonary valve atresia or stenosis; and patent ductus arteriosus. The higher rates observed in Region 11 for these heart defects of lesser severity may result from differences between regions in the use of diagnostic tests and procedures, differences in reporting in medical records, or true higher rates in Region 11. Further analyses are underway to assess what may be contributing to these observations. Other birth defects with statistically significant differences between regions were microphthalmia (highest rate in Regions 8); pyloric stenosis (highest rate in Region 2); hypospadias or epispadias (highest rate in Region 3); obstructive genitourinary defect (highest rate in Region 3); and congenital hip dislocation (highest rate in Region 9).

# History and Program Description

In April 1991, three infants were delivered in a 36-hour period in one facility in Brownsville, Texas with anencephaly, a birth defect in which much of the brain is missing. Astute clinicians recognized that this was excessive for this time period and facility, and they alerted the Texas Department of Health (TDH) of this cluster (an observed or reported excess of a health condition). In response, TDH, in cooperation with local officials and providers and the Centers for Disease Control and Prevention (CDC), conducted a thorough epidemiologic investigation of neural tube defects in the area of concern. This area was comprised by Cameron County (which includes Brownsville) and Hidalgo County, the two most southeastern Texas counties that border Mexico. Compared with the United States, high rates of neural tube defects were confirmed for the area, especially Cameron County in 1991. The investigation underscored the need for background data on birth defects in Texas. In response to this cluster and the need for better data, and in recognition of the enormous resources routinely put forth by TDH in the investigation of birth defects clusters statewide, the Texas Legislature passed the Texas Birth Defects Act in 1993.

Out of this statute, the Texas Birth Defects Monitoring Division was created. The mission of this division is to identify and describe the patterns of birth defects in Texas, and to collaborate with others in finding causes of birth defects, working towards prevention, and linking families with services. This includes creating and maintaining the Texas Birth Defects Registry, monitoring for the excess occurrence of birth defects, conducting cluster investigations, and referring identified children and their families for services. The Texas Birth Defects Registry has been collecting data on birth defects in Texas since 1995, beginning with a pilot area encompassing the Lower Rio Grande Valley and the Greater Houston area (approximately 35% of live births in Texas). In 1997, active surveillance expanded to include parts of the state accounting for 80% of Texas births, and finally in 1999, data collection efforts went statewide.

The Texas Birth Defects Research Center was established in late 1996 at TDH through funding from the Centers for Disease Control and Prevention. Through this center, researchers conduct epidemiologic studies in Texas and collaborate with seven other centers nationally to find preventable causes of birth defects.

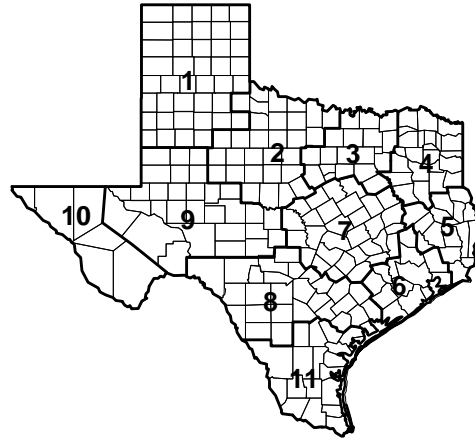
# Methods

## Scope of this Report

This report presents information on selected birth defects among deliveries during 1996 and 1997 to women who lived in areas of the state where the Texas Birth Defects Registry was active. For 1996 deliveries, the birth defects registry was active in Public Health Region 6, which includes Houston and Galveston, and Region 11, which includes the Lower Rio Grande Valley, Corpus Christi, and Laredo (see Figure 1). For 1997 deliveries, the registry was active in Region 2 (Abilene and Wichita Falls), Region 3 (Dallas-Fort Worth), Region 8 (San Antonio), Region 9 (Midland-Odessa and San Angelo), Region 10 (El Paso and Big Bend), and Region 11.

This report includes information in the Texas Birth Defects Registry as of November 23, 1999.

**Figure 1:** Texas Public Health Regions



## Case Definition

To be included as a case in the Texas Birth Defects Registry, all of the following criteria must be met:

- The mother's residence at the time of delivery must be in an area covered by the registry. Areas covered for deliveries in 1996 and 1997 are described above.
- The infant or fetus must have a structural birth defect monitored by the registry or fetal alcohol syndrome.
- The defect must be diagnosed prenatally or within one year after delivery. An exception is fetal alcohol syndrome, which must be diagnosed within the first six years of life.
- The outcome of pregnancy must be a live birth or, if the outcome was not a live birth, the fetus must have a gestational age of at least 20 weeks or a birth weight of at least 500 grams.

The registry also collects information on birth defects found among induced pregnancy terminations before 20 weeks gestation that occur in the facilities we access. Induced terminations before 20 weeks gestation are not included in the data shown in this report because of incomplete ascertainment, due to the hospital focus of our surveillance. However, these data are used in research, special analyses, cluster investigations, and prevention projects.

## Data Collection

The Texas Birth Defects Monitoring Division uses active surveillance. This means it does not require reporting by hospitals or medical professionals. Instead, trained program staff routinely visit medical facilities where they have the authority to review log books, hospital discharge lists, and other records. From this review, the staff create a list of potential cases. Program staff then review medical charts for each potential case identified. If the infant or fetus has a birth defect covered by the registry, detailed demographic and diagnostic information is abstracted. That information is entered into the computer and submitted for processing into the registry. Quality control procedures for finding cases, abstracting information, and coding defects help ensure completeness and accuracy.

Records in the birth defects registry were matched to birth certificates and fetal death certificates filed with the Texas Bureau of Vital Statistics. When a record in the birth defects registry matched a birth or fetal death certificate, and information was not missing from the matching certificate, the analysis for this report used demographic data from the birth or fetal death certificate for the following: date of delivery, sex of the infant or fetus, mother's date of birth, mother's race/ethnicity, and mother's county of residence at the time of delivery. When a registry record did not match a birth or fetal death certificate, or when information was missing from the certificate, then this report used demographic data abstracted from medical records. Regardless of the source of demographic information for this report, all diagnostic information was abstracted from medical records.

Surveillance activities in Region 11 were conducted through a cooperative agreement with the Texas Neural Tube Defect Project.

## Data Analysis

Results are presented for selected defects monitored in 1996 and 1997, regardless of whether the defect occurred alone or together with others. Because an infant or fetus often has more than one defect, and not all monitored defects are included in these analyses, it is not meaningful to sum all diagnostic categories in the tables to obtain the total number of children with birth defects.

Tables include the number of cases found, the estimated prevalence per 10,000 live births, and the 95% confidence interval for the prevalence. Birth prevalence (also referred to as rate) was calculated as follows:

$$\frac{\text{cases}}{\text{total number of live births}} \times 10,000$$

The prevalence is only an estimate of the true prevalence, which is unknown. The confidence interval contains the true prevalence of a birth defect 95% of the time. A wide interval indicates the uncertainty stemming from small numbers. This report displays 95% confidence intervals based on the Poisson distribution. Poisson regression was used to identify statistically significant differences in prevalence between groups, for example, between mothers of different ages, or between males and females.

## Limitations of these Data

Pregnancies that end before 20 weeks are excluded from the case definition. Since some conditions may be prenatally diagnosed and the pregnancy terminated prior to 20 weeks, the observed rates may underestimate true occurrence.

With the exception of fetal alcohol syndrome, the registry only includes defects that were diagnosed prior to the first birthday. Diagnoses made after the first birthday are missed. Deliveries and diagnoses that occurred outside of the registry coverage area, or in facilities the registry does not access, are also missed.

During both 1996 and 1997 the registry underwent major expansions. In 1996, the list of conditions monitored increased from a few selected defects to all major structural defects. In 1997, five regions of the state began their first year of data collection.

Region 11, which includes the Lower Rio Grande Valley, Corpus Christi, and Laredo, was covered by the registry during both 1996 and 1997. No other region of the state was covered both years. This means that for this report Region 11 has twice the impact it would normally have.

Data for Region 11 in 1996 shown in this report may differ from data shown in the special report "Birth Defects in the Lower Rio Grande Valley" (published December 1998). This is because registry records may be added, removed, or changed as additional information becomes available. Furthermore, for some birth defects, the group of BPA codes used to define the defect differs slightly in this report compared to previous reports. See Appendix B for the BPA codes used to define the birth defects shown in this report.